California Health and Human Services Agency Gavin Newsom, Governor

HCAI Department of Health Care Access and Information

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NOTICE OF PUBLIC MEETING: HEALTHCARE PAYMENTS DATA PROGRAM DATA RELEASE COMMITTEE

January 10, 2022
DRAFT MEETING MINUTES

Members Attending: Janet Coffman, Professor, Institute for Health Policy Studies; Larry deGhetaldi, Vice President Government Medical Affairs; Miranda Dietz, Project Director, California Simulation of Insurance Markets microsimulation model (CalSIM); Genia Fick, Vice President, Quality; Cora Han, Chief Data Officer; Jan Hanley, Director of Research Programming; Terry Hill, Physician Consultant, Researcher, Writer; Koh Kerdsri, Vice President, Risk Adjustment Operations, Compliance & IT; Barbara Koenig, Professor Emerita of Bioethics; Nuriel Moghavem, Clinical Instructor of Neurology; Daniel Ruiz, Vice President, Operations Quality.

Presenters: Michael Valle, Chief Information Officer and Deputy Director, HCAI; Dionne Evans-Dean, Cost Transparency Section Manager, HCAI; Sandra Bannerman, Research Data Manager, HCAI; Merry Holliday-Hanson, Research Scientist Supervisor, HCAI; Wade Iuele, HPD Consultant, HCAI; Chris Krawczyk, Chief Analytics Officer, HCAI; Andy Potter, Research Scientist Supervisor, HCAI.

Public Attendance: 32

Agenda Item I: Welcome and Meeting Minutes

Nuriel Moghavem, Data Release Committee (DRC) Chair

Nuriel Moghavem, DRC Chair, welcomed the committee and members of the public. The committee members did roll call with a brief introduction for the two members who were absent at the inaugural meeting, Larry deGhetaldi and Miranda Dietz. The chair went over the virtual meeting ground rules.

The committee reviewed and approved the meeting minutes from the December 1, 2022, DRC Meeting. The motion was made by Terry Hill and seconded by Genia Fick.

The following nine members approved the motion: Janet Coffman, Genia Fick, Cora Han, Jan Hanley, Terry Hill, Koh Kerdsri, Barbara Koenig, Daniel Ruiz, and Nuriel Moghavem.

The following two members abstained from voting for the motion: Larry deGhetaldi and Miranda Dietz.

Questions and comments from the committee

There were no questions or comments from the committee.

Public comment:

There was no public comment.

Agenda Item II: December Meeting Recap & Program Updates

Nuriel Moghavem, DRC Chair

The chair provided a brief overview of the topics discussed at the December meeting, such as the Bagley Keene Open Meeting Act; conflict of interest and the Form 700 disclosure form; a Healthcare Payments Data (HPD) Program and data access and release overview; and the DRC role and responsibilities and the benefit of All-Payer Claims Databases (APCD) to states.

The chair also discussed the follow up items presented at the December meeting and assured the committee that some of these items will be discussed at the January meeting.

Michael Valle, HCAI Chief Information Officer and Deputy Director, introduced the new HPD Policy Lead, Olivia Harrell-Nash, and provided opening remarks for the meeting's topics; and shared a proposed timeline of anticipated topics for future Data Release Committee meetings, which will allow HCAI to obtain input from the committee on key deliverables. He also noted that additional topics can be folded into the timeline as needed.

Questions and comments from the committee

The committee discussed the differences between the public reporting data, which will be openly available to anyone in the public, and the non-public HPD data that falls under the purview of the DRC. The committee confirmed that today's meeting would include a further discussion around what data will be in the system, how the data will be stored, and what the data governance policies around the enclave will include. Lastly, the committee noted the importance of including a future discussion around how the program conducts public engagement that educates the public about the use of patient data.

Public comment:

There was no public comment.

Agenda Item III. Key HPD Data Elements

Dionne Evans-Dean, Cost Transparency Section Manager, HCAI

Dionne Evans-Dean, Cost Transparency Section Manager, HCAI, provided a review of the HPD Program including the APCD Common Data Layout (CDL), which details a comprehensive explanation of the data elements collected, and HCAI's data submission guide, which documents additional information not included in the APCD-CDL. Dionne also noted that there is an HPD reporting manual that provides comments related to the implementation of regulations for data collection.

<u>Questions and comments from the committee</u>

The committee noted that data quality standards are important, and that some data elements may be more accurate than others. They requested a future discussion on the accuracy of each of the data elements. The committee had a robust discussion about the importance of collecting accurate race and ethnicity, sexual orientation, and gender identity (SOGI), and disability status data to support efforts to improve health equity. HCAI noted the department's participation with the National Association of Health Data Organizations (NAHDO) which develops the APCD-CDL. Currently the specifications for the race and ethnicity are based on Center for Disease Control and Prevention (CDC) and Office of Management and Budget (OMB) standards and HCAI looks forward to upcoming expansions that allow California to collect more granular that can roll-up to standardized categorical groups. It was noted that there are many national efforts about the categorization of race and ethnicity, and committee members noted that HCAI should work with sibling organizations, such as the Department of Managed Health Care (DMHC) who are currently working on implementing 13 health equity measures for health plans to report on.

The committee also discussed the status of the submission of data and informed that most of the submitters are in the production phase for historical data files and submitters are moving towards beginning ongoing monthly file submission.

The committee also inquired if the HPD will include both approved and denied claims and what is the limitation with denied claims. Approved and partially denied claims will be included. Modifications to an original claim, such as replacements and reversals will also be included.

Finally, the committee asked for clarification on whether cost referred to the price of services or the cost to care for patients. It was noted that the database will have robust information from charge amounts, paid amounts, allowed amounts, and premiums.

The committee also raised the question about how the statutes and regulations contemplate access to Entity and Financial Information (EFI) data and HCAI staff responded that this would be discussed in the regulations portion of the meeting.

<u>Public comment:</u>

There was no public comment.

Agenda Item IV: HPD Data Access and Release Regulations

Sandra Bannerman, Research Data Manager, HCAI

Sandra Bannerman, Research Data Manager, HCAI, gave an overview of the HPD data access use and release regulations including sharing the anticipated data access and release timeline, which shows the various stages and parallel work that began in 2022 and lays some of the groundwork for the DRCs role, timing, and next steps.

Questions and comments from the committee

The committee had a detailed discussion around the HPD Data Access Framework, seeking further clarification regarding direct and indirect identifiers, limited, and standardized limited datasets as well as research, identifiable data, and confidential data in terms of the contemplated use cases for each. It was noted that direct identifiers are tied to HIPAA, such as, a name, while an indirect identifier could be race combined with gender or, for example, a pregnancy diagnosis code, which would let someone know that the person is female. Indirect identifiers are not obviously identifiable, like name or address, but could subtly identify a person.

In terms of standardized limited datasets HCAI determines what variables fall into a standardized limited data set and the proposed use for that dataset. Entities that request this kind of dataset will have to justify that their proposed use is consistent with HPD's program goals, an area that the DRC will consider in reviewing requests. A custom limited dataset will be a dataset that is available if the standardized dataset does not meet the needs of the requesting entity, the entity will be able to select the variables they are interested in.

The committee inquired if the non-confidential data was aggregate, non-record level data. The data is not record level for patients or individuals, but it may include record-level data about a payer or provider. HCAI noted that this is different than publicly available de-identified data. The California Health and Human Services Agency (CalHHS) Data Deidentification Guidelines are used as the standard to aggregate confidential data for sufficient deidentification prior to publication. For the data release framework overall, the committee requested that HCAI share use cases with the committee to highlight the processes and clarify the role of the committee.

The committee discussed the varying access pathways for standard and custom limited datasets, noting that datasets will be available via the enclave or direct file transmission, but to ensure appropriate privacy protections, all datasets being accessed by direct file transmissions require DRC review. The committee was informed that HCAI will be encouraging requestors to use the enclave as opposed to direct file transfer. Additionally, the committee discussed that confidential data is an umbrella term that covers research identifiable data and limited data, with researcher identifiable data being a subset of confidential data. It was noted that research identifiable data is the most identifiable and most protected data, and that the framework is organized by type of access, direct file transmission or enclave, and the categories are based on statute.

The committee also discussed the review process that will be needed for various datasets. They discussed that while requests would need to be reviewed by the DRC, and specific types of data requests will need to be reviewed by the Committee for the Protection of Human Subjects (CPHS), an entity may decide to also have the request reviewed by their own Institutional Review Board. The committee discussed the role of the Department of Health Care Services (DHCS) in reviewing requests for Medi-Cal data. It was noted that it is unclear at this time whether DHCS will be reviewing requests for non-confidential Medi-Cal data, and HCAI will follow up on this item. The committee also noted that levels of review are important, however, minimizing administrative delays in the review process is also critical to ensure data analyses are timely and relevant. The committee talked about considering previous requestors, or those who must submit more than one data request, receiving an accelerated review, and it was discussed that this could be specified in the data release policies and procedures.

The committee was informed that HCAI is proposing in regulation that the definition for researcher be inclusive of various backgrounds, defining researchers as having a bachelor’s degree or above in certain fields, such as physical sciences and life sciences, in addition to requiring requestors to provide information about their entity affiliation. While any entity can apply for a data request, a determination will need to be made if the request fits with the definition of a “researcher” and “research project”.

The committee had a discussion on patient privacy, including discussion about if patients will be given the opportunity to opt out of the data sharing. Patients will not have the opportunity to opt out of data sharing; California-licensed health plans and insurers are required to provide data to HPD, and if a requester meets the requirements in statute and HCAI regulations, then they may be able to receive the data. It is not required for non-California regulated plans to submit to HCAI, although they may request and apply to be voluntary submitters. HCAI has the discretion to accept voluntary submitter data. Additionally, the committee asked how the public would be informed about the HPD initiative. It was noted that the DRC, as a public body, will inform the public through conducting public meetings. It was also noted that the public HPD Advisory Committee includes members representing consumers.

The committee discussed other privacy and security related topics, including the data ownership, how the DRC would ensure that institutions had the appropriate safeguards in place to protect the data, and who would be liable if there was a data breach. It was noted that regulations will have security standards that an applicant will have to meet to receive a direct transmission of confidential data that HCAI will enforce through a data use agreement with data recipients. Data use agreements may have provisions for damages and liabilities.

Finally, the committee discussed EFI, and it was noted that though it is not a defined term in statute, it is a general program term, and that the regulations also do not define EFI because they are focused on patient and consumer protections, the committee will have the opportunity to discuss how EFI requests will be reviewed as part of data release criteria, policies, and procedures.

Public comment:

There was no public comment.

Agenda Item V: HPD Confidential and Non-Confidential Data

Merry Holliday-Hanson, Research Scientist Supervisor, HCAI

Merry Holliday-Hanson, Research Scientist Supervisor, HCAI, gave an overview of HPD Confidential and Non-Confidential Data including the Framework for HPD data access.

Questions and comments from the committee

The committee had a robust discussion around data confidentiality including the level of aggregation, assessment of reidentification risk, how the CalHHS deidentification guidelines are applied and whether those guidelines can be made available to data requestors. The committee commented on the importance of geographic granularity, including going down the census tract level, due to the intersections of socio-economic factors, which are related to negative health outcomes.

The committee also had a broad discussion on the various types of sensitive data and the importance of further defining these categories. It was discussed that additional input from the DRC is needed to understand the types of conditions, and other factors, that could be categorized as “sensitive”, because the enabling statute does not specify. The committee suggested looking at how other organizations have defined sensitive conditions and noted that sensitive conditions may need to be reviewed on a case-by-case basis.

Public comment:

There was no public comment.

Agenda Item VI. HPD Data Access Methods

Wade Iuele, HPD Consultant, HCAI
Chris Krawczyk, Chief Analytics Officer, HCAI

Wade Iuele, HPD Consultant, HCAI, provided an overview of the HPD Secure Data Enclave. Chris Krawczyk, Chief Analytics Officer, HCAI, provided an overview of direct transmission of HPD files, including an overview of the DRC’s role whenever direct transmission is requested.

Questions and comments from the committee

The committee discussed the capabilities of the secure data enclave, including storage restrictions and setup procedures, the process for reviewing data removed from the enclave, and the technology architecture of the enclave. It was noted that the enclave is in the final stages of procurement and more information on the capabilities will be provided later.

The committee inquired about other successful examples of data enclaves in use. HCAI noted that there are other states that operate APCDs with enclaves, however, none of the other states have California's volume of data. HCAI intends to ensure that the use of the enclave can scale to the volume needed in California.

The committee asked whether the HPD will be a repository that is required to post data noting that research that is funded by the National Institutes of Health (NIH) and other federal programs are required to share their data at the conclusion of their projects. The chair will follow up with HCAI regarding this issue.

The committee asked about what kind of protections and disaster recovery redundancies are in place for the enclave technology. It was noted that as part of the procurement, HCAI has very high standards for security, continuity, and resiliency. More details will be available once procurement is complete.

The committee suggested that institutions be provided the opportunity to take ownership for data security requirements by creating an agreement that encompasses all projects affiliated with an organization, to relieve individual requestors from having to provide this information redundantly. The committee recommended a mechanism to prevent downstream misuse of the data, to ensure it is used in accordance with a specific project and only that project. The committee would like key performance indicators to define and measure success after a data project is complete once access to the data becomes available.

Public comment:

There was one public comment asking if datasets in the Enclave would have masked individual identifiers, such as a patient or record ID number. It was noted that datasets in the Enclave will include unique record numbers that cannot be tied back to any actual patient identifiers.

Agenda Item VII: HPD Data Uses

Sandra Bannerman, Research Data Manager, HCAI
Andy Potter, Research Scientist Supervisor, HCAI

Sandra Bannerman, Research Data Manager, HCAI, gave an overview of HPD data uses. Andy Potter, Research Scientist Supervisor, HCAI, gave an overview of the planned public reporting and internal use of HPD data, including the planned public dashboards that will include metadata as well as chronic conditions and healthcare utilization displayed in various ways.

Questions and comments from the committee

The committee asked if there will be notes or metadata available to the public to see what kind of data is included in the reporting of chronic conditions. HCAI noted that chronic condition prevalence will be calculated using the chronic conditions warehouse definitions available on the Centers for Medicare and Medicaid Services (CMS) website. The committee asked if data users will be made aware that the chronic conditions definitions will be conforming to CMS guidelines and HCAI responded that this explanation will be part of the data dictionary. The committee suggested that the inclusion of a common risk assessment methodology is important.

The committee inquired about the steps taken prior to releasing new data elements, that may be lacking in quality and completeness, and how it may impact the ability to publish the metrics. HCAI noted that there are quality and validation checks at various stages in the process. Additionally, HCAI is required to submit a report to the California Legislature by March 2024 detailing the completeness of the database and identifying gaps and recommendations for improvement. The committee was informed that the public reports would include commercial data, Medi-Cal, and Medicare plans metrics.

The committee inquired about the intended audience of the public visualizations. Since there is a potential for them to be used widely, it was suggested that they be made as accessible as possible.

The committee was also informed that socioeconomic variables, such as income and housing data, would not be included in the initial public reporting portfolio.

The committee discussed any penalties that may be incurred by data requestors if data they are using is improperly disclosed. It was noted that HCAI is subject to numerous federal and state requirements related to data privacy and security, as data requestors will be, and that those include breach notification requirements. The committee asked for more information about the security controls and requirements for the HPD.

Public comment:

There was no public comment.

Agenda Item VIII: Next Meeting Topics and Discussion

Nuriel Moghavem, DRC Chair, provided a preview of the March DRC meeting agenda. Topics for the March meeting include:

- Treatment of Sensitive HPD Data;
- Data Privacy and Security; and

- Other topics of priority to the committee, time permitting.

Nuriel Moghavem, DRC Chair, also provided a list of follow up items, the list is as follows.

- Share CalHHS Data Deidentification Guidelines, HPD Reporting Manual, HPD Data Submission Guide, and APCD-CDL to members;
- Provide an update on NIH requirements for data sharing being supported by the HPD;
- Further detail on the definition of researcher;
- *Future topic for committee discussion*: Collection and quality of race, ethnicity, gender identity, and social determinants data;
- *Future topic for committee discussion*: Discussion on EFI, financial transparency, and the legal and antitrust implications; and
- *Future topic for committee discussion*: Definition of sensitive conditions and framework HPD can follow.

<u>Questions and comments from the committee</u>

The committee offered additional follow up items; the list is as follows.

- What are the benefits to California that should be prioritized by the committee that will assist with making decisions in reviewing data requests; and
- Request HCAI staff develop a communications packet to help members communicate the goal and progress of the HPD so that they may serve as ambassadors for HCAI.

The March meeting will be held on March 7 from 9:00 a.m. – 1:00 p.m. and will be fully virtual via Microsoft Teams.

<u>Public comment:</u>

There was no public comment.

Agenda Item IX: Public Comment for Items Not on the Agenda

There was no public comment.

The meeting adjourned at 12:37 p.m.